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14. ABSTRACT

The purpose of this project is to describe the meaning of prostate cancer treatment-related incontinence and impotence for low income African American and Latino men. Preliminary common categories between the Latino and African American men included erectile dysfunction and incontinence were the price that had to be paid to cure cancer, trusting God as a means of coping, context of incontinence as determinant of its acceptability (e.g. if due to illness, acceptable; if due to drunkenness, not acceptable), and ambivalence toward role of erectile function in masculine identity and transitional masculinity.

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I. INTRODUCTION

Incontinence and impotence are potential side effects of the most common treatments for prostate cancer. Both incontinence and impotence can occur after surgery or radiation therapy, whereas impotence along with loss of libido can occur with hormone therapy; these outcomes can adversely affect men's quality of life. Discussing these outcomes is necessary to assist men with prostate cancer in making treatment decisions and coping with these symptoms when they occur. The primary purpose of this project is to describe the meaning of prostate cancer treatment related incontinence and impotence for low income African American and Latino men. This will begin the process of discovering influential variables that will support development of culturally appropriate educational material. The Principal Investigator (PI) hypothesizes that cultural, ethnic, religious, educational, and socioeconomic differences affect the viewpoint of these groups. In particular, cultural concepts such as machismo, stoicism, and fatalism may influence patients' perceptions. The research strategy being used is qualitative descriptive with applied ethnographic and phenomenological overtones.

II. BODY

Task 1. To elicit African American and Latino men's perspectives on prostate cancer treatment- related incontinence and impotence. (Months 1-19)

a. Identify and recruit potential participants (Months 1-15)
b. Conduct initial interviews (Months 2-16)
c. Conduct second interviews (Months 5-19)

Accomplishments: We have been able to enroll a total of 60 Latino men and 35 African American men with whom the initial interviews have been completed. The target recruitment of 60 was reached for Latino men. However, because of several unanticipated circumstances we were not able to enroll and interview 60 African American men. There was an enrollment suspension of 10 months in the IMPACT program from which we were recruiting. Because, IMPACT's enrollment is over 50% Latino, we were able to reach our target for this group despite the enrollment suspension, but because the number of African Americans is much smaller, we were not able to meet that target. To compensate, we continued recruiting African American participants at the West Los Angeles Veterans Administration Medical Center and through ethnic-specific newspapers allowing us to recruit a total of 35 African American men. This sample size is very adequate to obtain informational redundancy as required by the descriptive qualitative approach being used in this study. Generally 20-30 participants are considered adequate. [1] A total of 24 second, confirmatory interviews have been completed. To date, 23 (20 Latino, 3 African American) participants have been lost to follow-up due to a variety of reasons with the primary one being an inability to recontact men because of changed addresses and telephone numbers.

Task 2. To identify themes emerging from the interview data (Months 2-31)

a. Verbatim transcription of interview tapes (Months 2-24)
b. Translate Spanish transcripts (Months 2-26)
c. Prepare transcripts for N Vivo entry (Months 3-28)
d. Enter data into N Vivo (Months 3-28)
e. Line-by-line coding of data and constant comparative technique (Months 3-28)
f. Identify themes related to beliefs about urinary, sexual, and bowel function, and masculinity (Months 4-30)
g. Verify themes with participants (Months 5-31)

Accomplishments: Transcription of all 95 initial interviews and 20 second interviews has been completed. Translation of 50 of the initial Latino transcripts has been completed. Line-by-line coding continues to be accomplished with color-coding and highlighting for the documents. From this, codes are copied and pasted in category documents and the PI is maintaining a log of all analysis decisions. Working with the study team and a doctoral student in nursing, initial themes related to urinary and sexual issues and

masculinity have been identified. Emergent themes and categories are being verified and modified where needed with 20 participants in the second interviews.

Task 3. To describe concepts of meaning and their underlying structure (Months 20-36)

a. Cluster themes into conceptual categories (Months 20-34)
b. Compare categories across interview transcripts (Months 20-34)
c. Identify clusters related to incontinence and impotence (Months 20-34)
d. Develop narratives describing the meanings of incontinence and impotence as it has emerged from the data along with the underlying cultural beliefs (Months 30-36)

Accomplishments: Analysis of the data is ongoing using close and multiple readings, line-by-line coding, development of categories and constant comparison within and between transcripts. Currently we are working on deepening the analysis of two prominent themes that have emerged from the data. One is on masculine identity shifts and the other is related to the functions of spirituality in living with prostate cancer treatment-related symptoms among low-income Latino men. The role of spirituality relative to meaning creation for prostate cancer treatment-related symptoms was an unexpected finding that we are pursuing in-depth. Please see Appendix 1 for an example of how this theme is being developed. The NCE will be used to complete translation of follow-up interviews, continue increasing the depth of analysis and development of additional manuscripts. We will continue this in-depth analysis to fully describe the processes by which the men participating in this study make meaning of their treatment-related symptoms within the context of their social and cultural backgrounds.

III. KEY RESEARCH ACCOMPLISHMENTS

Findings

Preliminary common categories between the Latino and African American men included:

- erectile dysfunction and incontinence were the price that had to be paid to cure cancer,
- trusting God as a means of coping,
- context of incontinence as determinant of its acceptability (e.g. if due to illness, acceptable; if due to drunkenness, not acceptable), and
- ambivalence toward role of erectile function in masculine identity and transitional masculinity.

The concept that is emerging relative to masculine identity in the face of treatment-related erectile dysfunction is analogous to the concept of "priority shift" within the quality of life literature. While men, both Latino and African American remain hopeful that erectile function will return, captured under the code of "hopeful waiting", men also talk about contextual masculinity and shifting priorities as they work to reframe what it means to be masculine. Contextual masculinity is seen in the transcripts when men tell about conversing with other men about women and sex as a man able to have intercourse and then when talking about the things that are important for a man to do as taking care of one's family and providing support. Masculinity can be seen to be multidimensional in these transcripts and the shift that is occurring is one of reprioritizing the emphasis of importance from the physical functioning component to the more relational ones. We are continuing to explore how age and occupation may influence this and for the African American men, how social movements such as the Million Man March may provide an additional influence on their process of reprioritizing masculinity.

IV. REPORTABLE OUTCOMES:

- Based on work from this project we have received intramural funding to investigate symptom clusters related to prostate cancer treatment among low-income Latino men and the impact of prostate cancer treatment-related symptoms on low-income Latino couples. This work is currently in progress.
- Also, we were recommended for funding by the Department of Defense on our latest resubmission of our proposal to investigate the impact of prostate cancer treatment-related symptoms on low-income, Latino couples.

V. CONCLUSION:

Little is know about the impact of incontinence and impotence from prostate cancer treatment on the lives of low-income men from other cultural backgrounds nor how cultural beliefs surrounding urinary, bowel, and sexual function and the definitions of masculinity influence how these symptoms are perceived. Even less known is how religious beliefs and spirituality as part of the cultural milieu may play a role in the meaning of these symptoms. Understanding what incontinence and impotence mean as they relate to beliefs and attitudes toward urinary and sexual, function is critical to understanding how prostate cancer treatment decisions may be influenced and how best to discuss these symptoms and intervene with low-income African American and Latino men. The results of this study are laying the foundation for the development of culturally appropriate educational and symptom management interventions for this population. They are suggesting that new approaches such viewing spirituality as a resource for maintaining control and working with the health care team or assistance with reprioritizing aspects of masculine identity to reframe masculinity within the context of prostate cancer treatment-related erectile dysfunction may be fruitful avenues to pursue.

REFERENCE

1. Creswell J. Qualitative Inquiry and Research Design. 1998, Thousand Oaks, CA: Sage Publications.

Appendix

1. Example of Development of Spirituality Theme

SUMMARY
Low-income Latino men appeared to successfully utilize their spirituality as a means of coping with their diagnosis of prostate cancer. Their initial reaction to the diagnosis was anxiety, primarily related to a fear of death, and their strong concerns about being able to support and not worry their family. Secondarily, many strongly expressed that they did not want to continue to agitate themselves with the uncertainty of their future. Therefore, their goal of taking the right attitude so that they could continue to maintain a positive sense of self took precedence over having an in-depth understanding of their disease or a prolonged pondering of the best treatment regiment, as has been seen in other populations. The vehicle for achieving their goals appeared to be turning over their destiny to God, which seemed to relieve their anxiety. Additionally, they divided the workload, with God being responsible for their destiny, while they were responsible for their daily care of their body, mind, and family. In essence, it seemed that in releasing control of their ultimate destiny, they were able to gain control of their daily lives. As has often been observed in people facing cancer, their spirituality became revitalized, giving them an expanded view of their world, and appreciation of their daily life and relationships. In this population, often linked with Latin machismo, they showed considerable tolerance for the side effects of surgery (e.g., incontinence and impotence), and often explored more creative ways of experiencing their manliness. Interestingly, although most of these men are from Mexico and generally of the Roman Catholic faith, this spirituality often did not appear to exist within the rituals of the church or with the priests, but as a personal connection with God.

PROCESS
Spirituality functions in this context by:

Process

I. Experience of Anxiety after being told that he has prostate cancer.

Patient #666. The most extreme reaction was a fieldworker who stated, "I felt like screaming, like running away." He described sensory distortion, including a loss of hearing and taste, and a feeling of "being outside his normal life". He said he argued with his wife about everything, had problems at work, and felt that there would be no cure for him.

Source of anxiety for Patient #666: about what my wife was going to do what, what was she going to do. I didn't think about me that something would happen to me but rather I thought of her. What was going to happen to her if I couldn't work.

1) Occurs not necessarily in the context of the church or with clergy.
2) After extreme anxiety, yields to the will of God.
3) The act of acceptance and turning over their destiny to God

II. Maintaining their self-image

A. Work
Patient #666. Strong ethic of coming to this country to work and support his family without being dependent on someone else. On being able to support my family and um on well no, not depend on what others give me but rather um one...I would tell myself I'm here to work.

B. Not be a Problem for his Family
Patient #666. Described that his prostate cancer would be "a problem I would give them" about what my wife was going to do what, what was she going to do. I didn't think about me that something would happen to me but rather I thought of her. What was going to happen to her if I couldn't work.

III. Experience of Spirituality Within the Context of Prostate Cancer

A. How did it change?
1. In the Moment
1.a. Sense of God working through the medical team.
Patient #666 This man described that he was unable to treat the cancer, but that God worked through the nurse in the IMPACT program. He states that it happened right then, and he felt "new". [I would say, my God why, if I know that I don't um... I don't have the means to be able to treat a cancer and no, no, no. It's not, it's not going to be possible, what are we going to do or what... and, and until then that um happened. Um thanks to God um right there through a nurse.
God works through intermediaries such as IMPACT, doctors.
2. In the Long Term

B. Sense of Rebirth/ Attaining life and help through faith.
Patient #666: See A1a. "I felt somewhat new." Now he had faith, "I had not had the treatment yet but I already felt that something good was coming for me."

C. Spiritual lessons learned in this experience.
Patient #666. I once again then see then I remembered about God again. when I was so bad, I would not remember about Him... before anything, before family well in God. (believe in God) As a man you first have to believe in God.
Give us...ttt the...the gift of life.

D. Grateful to God.
Patient #666. Grateful to God and IMPACT And who have given me the opportunity to see life more, more mmm more um...rather spiritual, to love

others. I believe that God has given me the opportunity to continue to still be useful here in this world...God um who gives us...who gives us all that, give us the opportunity to be in this life. (the opportunity to be alive)

E. Private experience vs. church/religious experience.

1) Process of Catholic church spirituality

Patient #741: Mm well...I thought that I was going to move forward um I've always been very positive and I hope I'm very Catholic, very religious um I strongly believe in the hope in the faith in Christ and I lean on Him and I said my Lord I place my life in your hands as I've always done so and You're going to help me to make the effort. Uh...my religion like that if one believes and makes an effort you can achieve it righ'?

OUTCOMES

God's work vs. their work

1) Practical: gives them peace when they turn their destiny to God; obtain control by giving up control to God; By giving up their ultimate destiny to God, they can get on with the other chores of taking care of their health (walking, going to dr's office, doing exercises for incontinence, eating well), which is their work and not God's work.

Patient #244: And I felt calm, I didn't feel scared or sad or anything. I just wanted to get better. Patient #244: No well now, now I've already come to terms, now I have no reason to worry if now I can't...

Patient #244: No it's worse (if you get sad) and going around what's this and what's that and the other you're undermining yourself and you're ending and no I gave it my all.

2) Once they are calmed, they can continue to be the people they have always been (not anxious, crying, worrying their family...) Having a worried attitude is seen as a flaw, and prevents them from accomplishing their tasks/work.

Patient #741: That's...that's my conviction, and...and...I'm not killing my brain, that there's this way no, no, no, no, move on, move on but doing something to avoid the problems.

Patient #550: Tries not to think of potential problems- whether or not it will resolve or a med will help. "I tell you one tries not to think too much in those things, and neither your mind suffers nor your thoughts."

Patient #741: All that I've completely devoted myself to recuperating and I've done everything that could be positive in my way of thinking or favorable.

Patient #244: And I put my all into it in order, in order to get better.

3) Gives them courage and hope.

Patient #741: I say well the comfortableness, I accept what comes as impossible, and what's not impossible I try to overcome it.

Patient 741: Patient #741: But um…I feel capable of overcoming any situation.

Patient #741: Mmm same with because you could see my pants were wet but I was conscious that it was a short term thing in other words I never, never lamented that I was going to be like that all the time.

Approach is less cognitive and more on getting their attitude better so they do not disturb themselves or their family.

4) Opens up/expands their perspective/ breaks up established ideas: idea of what a man is, relationship of sex, different priorities; a sense of not going back to an old way of thinking.

Patient #244: Thank God we have food to eat and all that.

Patient #244: Well now we don't think about sexuality, now the important thing is that we get along well, uh we have a good normal relationship trying to take things easy.

4a) Expanded view.

Patient #741: And, and now that, that we're overcome that little barrier um I'm living in a broadened horizon, more um…more illusions more, more concrete a bit more life, search um for more happiness without, without, without not in bad habits but rather to take more advantage of life. *Idea of expansion in spirituality (what life is, what can be experienced...) They deal with the personal constriction of their life perhaps by finding more expansion within its very personal moments (being with their wife rather than having intercourse with her) Is that the value often in the saints of finding spirituality in more simple things (see quote above). However, not seen as austere- -it is rich- -not needing as much adornment as before.*

Of Sexuality/relationships

Patient #741: I do, do in a given moment it's not going to function anymore the little apparatus well there are other ways of satisfying one...
If it doesn't function during sex, there are other ways of satisfying oneself sexually.

Patient #741: I've very much enjoyed her presence her attention her care and all that and well that's helped me a lot. Hadn't lived with his mother for 25 years, and she came home to support him. .. Generally improves relationships

Patient #741: If I, if I don't ejaculate but I see that the woman is happy by my side, that brings me more pleasure.

5) Social context of spirituality: Gives them a context, which is understood by the patient, their family, and community.

6) Grateful for what they had, realizing that some of those things may no longer be available to them (intercourse, working hard, lifting heavy objects, feeling vigorous and invincible).

7) More tolerance of difficulties following surgery or waiting for solutions for impotence or incontinence- patiently waits and hopes. Is this a negative in that they may not bring up problems to their doctor/nurse?

8) Accepts limitations without resentment.

9) Divides mental and physical. Cartesian philosophy.
Patient #741: To control I didn't, didn't leave myself loose to lets see uh I have urges to go to the bathroom no, no mentally I supported the physical. Am I explaining myself?

What it is not:
1) A lesson
2) A second chance?
3) Generally not a punishment
4) Not fatalism

Discussion:
The act of acceptance and turning over their destiny to God
Are they more tolerant of yielding to the idea that they are not in control, and can do it with less anger?? Or is it that it is their religion? Less illusion of being in control.

Did level of discomfort or anxiety relate to need for spirituality?

Not much time spent in anger. Seem to quickly accept. After they turned it over to God, felt at peace. More comfort with this. Isn't this contrary to machismo where they are in control? Spirituality is a way of obtaining control by giving up control to God.
Purpose of spirituality: to give peace, so that they could do what they had to do without hesitating or lack of courage or worrying their family. Helped them be positive and forward thinking.

Not discussed as a learning experience- or punishment- or means to bring him or family closer to each other or to God.

Helps them manage the immediate problems of life.

Importance of doing what you can.

Within the Judeo-Christian perspective- in particular Roman Catholic.

Did not discuss the specifics of this: a prayer, if it happened quickly...

SUMMARY: Goal of taking the right attitude so that they can be the person they are proud of being (not a bother to themselves of their family; perhaps the more expanded vision of their machismo) perhaps more so than understanding the disease or pursuing the best surgeon (not an option for them anyway). Turning their destiny to God is a vehicle for doing this and is consistent with their belief system. Within this, they are able to find a more expanded definition of their world. Does this have to do with a feeling of more unity- mutual dependency/interconnectedness (with family and God) that is trustworthy – feel less alone?